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## Community Conversation: Community Education and Activation

Northwest Life Passages Coalition

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## COMMUNITY CONVERSATION: COMMUNITY EDUCATION AND ACTIVATION

**October 22, 2018**

**Health Education Center, Bellingham, WA**

### COMMUNITY CONVERSATIONS

In 2014, a community task force wrote a [Blueprint](#) that outlines steps to make Whatcom County a community of excellence for those with serious illness or facing death and their families.

The Blueprint has five pillars: Advance Care Planning, Clinical Care, Provider Training, Community Culture and Activation and Financial Sustainability.

Many organizations are involved with implementing various aspects of the Blueprint. The Northwest Life Passages (NWLP) Coalition provides a platform for Blueprint implementation by strengthening partners' shared commitment to the vision, facilitating coordination among programs and initiatives and fostering ongoing learning and innovation.

As part of those goals, the NWLP Coalition hosts community conversations on Blueprint pillars several times a year. Our intent is to share the progress that has been made and the challenges we still face, and to listen to community members' ideas, suggestions and concerns.



About 25 people participated.

### WELCOME

Sarah Bear, Director of the RN to BSN Program and Palliative Care Institute at Western Washington University, welcomed the group and explained the purpose and format: to have small group conversations about key aspects of palliative care and end-of-life and share reflections, ideas, and suggestions.

Mary Ann Percy gave an overview of the history of the NW Life Passages Coalition and its Blueprint.

### SMALL GROUP DISCUSSIONS IN "CONVERSATION STATIONS"

There were 5 stations with different topics, and NWLP Coalition members facilitated a 20-minute conversation at each station.

- Talking with medical providers
- Talking with family/loved ones
- Health care agents
- Cultural barriers and supports
- End-of-life "wish map," stories and experiences

→ For more detail on the conversations, please see the chart on pages 3-4

### LARGE GROUP REFLECTION AND DISCUSSION

Sarah invited participants to share their key learning or takeaways from the discussions.

## Reflections and Comments:

- Importance of building education into talking with younger people, even highschoolers. Kids talk to their parents, so discussions are prompted that way too.
- Struck by how many places there are to have these conversations – employers, younger people – there are lots of opportunities to be talking.
- There were marvelous stories at the “wish map” table. It’s a reminder that our experiences shape us, and the power of narratives and stories if we let in their full impact.
- Struck by the ease of the conversations, as if all “coming from a common place.”
- That half the people haven’t completed an advance care plan.
- People [patients] are often in turmoil; it’s nice to know there are people with the resources and skills to help.
- In the past, we would not have had a conversation about advance care planning. It feels like progress is slow, but as a community we are moving in the right direction.
- Struck by how many advocates are here and involved in this work.
- We need some new tactic to talk with younger people.
- Reminder that community members create a kind of accountability for doctors and nurses. The more community members ask, the more providers have to respond and engage.
- I’m realizing I need to pull out my advance directive. I did it a while ago and a lot has changed.
- It’s important to discuss [end-of-life wishes] with family even if they are geographically far away. Because we live far away from each other, we tend to spend our time together doing other things. I want to have a conversation with my brothers.
- I rolled my eyes when I realized it was going to be a “participatory thing” but actually enjoyed the discussions.
- Importance of bringing the message to the community, especially underserved communities and communities of color. We have a collective responsibility to promote outreach.
- It’s fun to have the freedom to talk about [end-of-life]. It feels good to talk about death openly.
- Appreciate that the conversation has shifted. It’s easier to jump in – not starting at square one. My next step is to have more casual conversations with the people around me.
- Normalizing the conversation about death is valuable. There’s an analogy with sex ed; just like talking about sex doesn’t make you pregnant, talking about death doesn’t make you die.
- My husband is a doctor and says his colleagues don’t want to talk about [end-of-life]. It’s heartening that new doctors are required to get some education around this.
- We’ve come a long way.
- It’s important to express wishes, no matter how small they may seem, not fearing they are “silly” requests. Being specific is OK, or adding in things that aren’t on the document.
- Learning about advocates/health care agents for people who don’t have family or close friends to name.
- Bringing up [advance care planning] is a gift to providers. It’s hard for them, so it helps if patients ask or talk about it, helps normalize it both for community members AND for providers.

## FEEDBACK ON FORMAT

### Plus (worked well):

- Different tables with different people and different issues
- Openness within the group
- Conversations felt easy

### Delta (change):

- Allow more time for each conversation.
- Attendance was low – increase and/or modify outreach.
- Add in a way to focus on what’s next, what are action steps – how to carry it forward.

## Community Education and Activation

### A Community Conversation hosted by the NW Life Passages Coalition

Station	Key Info/Concepts	Possible Activities	Handouts/supplies/tools	Facilitator/ station “hosts”
1. Talking with medical providers	<p>SHARE: People can – and should -- initiate conversations with their medical provider(s) about their end-of-life wishes.</p> <p>SOLICIT: What would make talking with your doctor easier?</p>	<p>Discussion around prompt questions</p> <p>Role play</p>	<p>Index cards with questions</p> <p>Randy Curtis article – <b>JAMA Internal Medicine</b> – supplemental materials have the questions.</p> <p>Conversation Project’s <a href="#">How to Talk with Your Dr</a> <a href="#">Conversation Project’s How to Talk with Your Doctor</a></p>	Hilary, Sharmon, Nancy
2. Talking with family/loved ones	<p>SHARE: People can – and should -- initiate conversations with their families and loved ones about their end-of-life wishes.</p> <p>SOLICIT: What would make talking with family members easier?</p>		<p>Conversation Project’s <a href="#">Conversation Starter Kit</a></p>	Sharon, Brenda, Elizabeth
3. Health care agents	<p>SHARE: Selecting a health care agent is a critical part of advance care planning.</p> <p>SOLICIT: What are some of the challenges around selecting and talking with a health care agent?</p>	<p>Brainstorm qualities of a “good” agent.</p>	<p>List of considerations when choosing an agent.</p> <p>Conversation Project’s <a href="#">Health Care Proxy</a></p>	Bobbi, Claudia, Mike, Jan

Station	Key Info/Concepts	Possible Activities	Handouts/supplies/tools	Facilitator/ station “hosts”
4. Cultural barriers and supports	<p>SOLICIT: What makes it hard to talk about dying in our culture (dominant American culture, or specific cultures within that)? What would help make it easier?</p> <p>Typically, when we host events, older, middle class, white community members attend. What can we do to engage a more diverse community?</p>	Brainstorm boards (write/draw) around cultural barriers and supports.		Chris, Cori, Australia
5. End of life “wish map”  Stories, experiences	<p>SHARE: Our own and others’ experiences shape how we feel about dying. Identifying what is important to us in our dying experience will help us create a meaningful advance care plan.</p>	<p>What are your wishes for end-of-life? What do you want your end-of-life story to be?</p> <p><u>Individual Maps</u>: Put yourself in the center; write/draw the things you want for your dying experience.</p> <p><u>Collective Map</u>: Brainstorm board (write/draw) what’s important at end of life.</p>	<p>Paper, markers, etc.</p> <p>Conversation Project’s <a href="#">Your Stories</a> <a href="#">Share Your Story</a></p>	Sharmon, Mary Ann, Jeanne